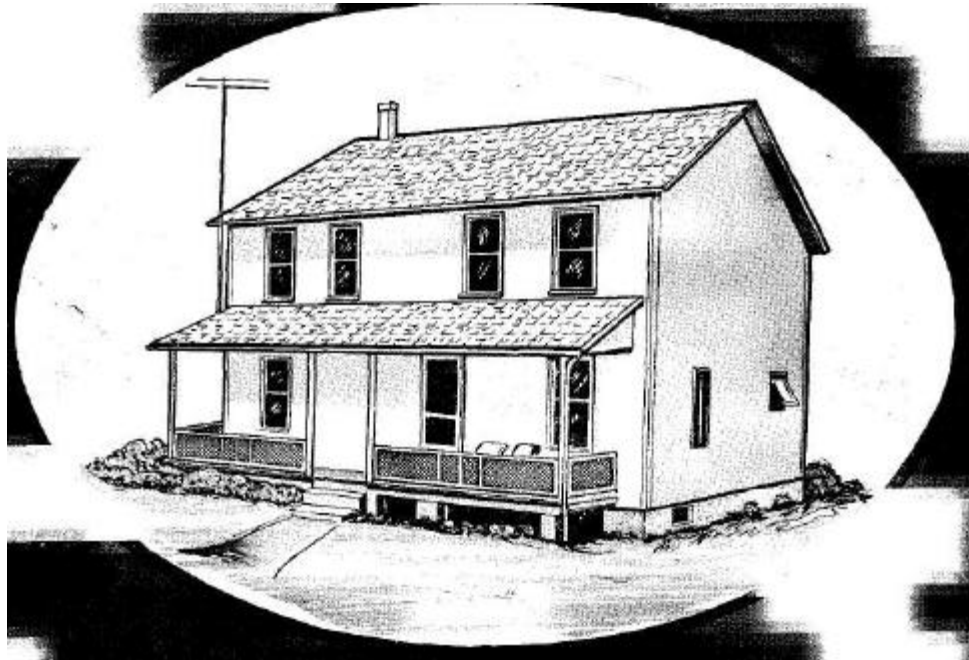


NEW NEIGHBORS

THE RETARDED CITIZEN IN QUEST OF A HOME



PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

WASHINGTON, D.C. 20201

1974

NEW NEIGHBORS

THE RETARDED CITIZEN IN QUEST OF A HOME

Edited by

Carolyn Cherington and Gunnar Dybwad

The Florence Heller Graduate School for
Advanced Studies in Social Welfare
Brandeis University



DHEW Publication No. (OHD)74-21004

**PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
WASHINGTON, D.C. 20201** 1974

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

The President's Committee on Mental Retardation was established by Executive Order of the President in 1966.

The Committee is composed of a chairman, 21 citizens members and five ex-officio members, appointed by the President to advise him on what is being done for the mentally retarded; to recommend Federal action where needed; to promote coordination and cooperation among public and private agencies; to stimulate individual and group action; and to promote public understanding of the mentally retarded.

Caspar W. Weinberger
Chairman

Mrs. N. Lorraine Beebee
Vice Chairperson

Mrs. Marianna Beach
Henry V. Cobb, Ph.D. Mr.
Robert A. Collier Mr. Frank
R. DeLuca Mr. Richard J.
Elkus Mr. Ralph J. Ferrara
Mr. Michael R. Gardner
Mr. Melvin Heckt Cecil B.
Jacobson, M.D. Mr. James
N. Juliana Mr. Aris (Bob)
Mallas Governor Thomas J.
Meskill Mr. Lloyd E. Rader,
Sr. Mrs. Louise R. Ravenel
Mr. William B. Robertson
Mr. Kenneth S. Robinson
Will Beth Stephens, Ph.D.
Mrs. Margaret B. Ulle
Miriam G. Wilson, M.D.

Ex-Officio

The Attorney General
The Secretary of Housing and
Urban Development
The Secretary of Labor
The Director of ACTION
The Director, Office of
Economic Opportunity

PROFESSIONAL STAFF

Fred J. Krause
Executive Director
Allen R. Menefee *Assistant*
Director, Program
Alfred D. Buchmueller
Miles Santamour
William Wilsnack
Raymond W. Nathan
Assistant Director,
Communications
Martin Bouhan
Mary Z. Gray
Stanley J. Phillips
Assistant Director,
Coordination

PREFACE

By Beth Stephens

Member, President's Committee on Mental Retardation

"New Neighbors: Retarded Citizens in Quest of a Home" is one important element in the effort of the President's Committee on Mental Retardation to facilitate and accelerate the transition to an era in which retarded citizens will be able to obtain a full spectrum of services in their home communities.

It does not cover all such services. Several essential services are or will be the subject of other reports by the President's Committee. For example, we have previously dealt with screening and assessment of young children at developmental risk in a publication so titled, and with the need to provide appropriate special education without unfair labeling and isolation of handicapped students, in the publications "Six-Hour Retarded Child" and "Very Special Child." Early intervention to correct defects in infants and young children will be treated in a report on a conference recently held under the Committee's sponsorship.

This book discusses philosophical and practical aspects of the retarded citizen's need for a home in the community, but does not purport to be a complete "how-to-do-it" manual. The Committee has in preparation a publication on community residential alternatives that will be a useful supplement to this volume for persons engaged in establishing group homes, and also calls to their attention "The Right to Choose," published by the National Association for Retarded Citizens.

The Committee does believe that the present book offers guidelines to all fair-minded Americans for welcoming their "new neighbors."

ACKNOWLEDGEMENTS

The Editors wish to acknowledge valuable editorial guidance provided by Dr. Burton Blatt, Professor and Director, Division of Special Education and Rehabilitation, Syracuse University; Hugh Lafave, M.D., Director, Eleanor Roosevelt Developmental Center, New York State Department of Mental Hygiene; and Robert Perske, Executive Director, Greater Omaha Association for Retarded Children.

To John Mercer we are indebted for invaluable editorial services.

Finally, our thanks go to Allen Menefee, our Project Officer, and to other members of the staff of the President's Committee on Mental Retardation for their patience and their helpfulness.

Carolyn Cherington
Gunnar Dybwad

LIST OF CONTRIBUTORS

Robert Audette

Director of the Bureau of Program Development and Evaluation, Massachusetts Division of Special Education, Department of Education, Boston, Massachusetts. **Carolyn Cherington**

Project Director for Developmental Disabilities, "The Roles and Functions of State Planning Systems," Brandeis University, Waltham, Massachusetts. **Gunnar Dybwad**

Gingold Professor of Human Development, Florence Heller Graduate School for Advanced Studies in Social Welfare, Brandeis University, Waltham, Massachusetts.

Donald Freedman

An attorney and Associate Director, Massachusetts Bureau of Developmental Disabilities, Executive Office for Administration and Finance, Boston, Massachusetts.

Ruth Freedman

A social science consultant and an author of *Serving Children with Special Needs*, U. S. Office of Child Development, 1973, and of *A Day Care Guide for Administrators, Teachers and Parents*, MIT Press, 1973.

Sheldon Gelman

Assistant Professor of Sociology, Pennsylvania State University, State College, Pennsylvania.

Thomas Graf

Executive Director of the Atlanta Association for Retarded Children, Atlanta, Georgia.

Thomas Holland

Director of the Human Services Design Laboratory, Case Western Reserve University, Cleveland, Ohio.

Jennifer Howse

Administrator of the Developmental Disabilities Program, Florida Division of Retardation, Department of Health and Rehabilitative Services, Tallahassee, Florida.

Brian Lensink

Director, Douglas County Office of Human Services, Omaha, Nebraska.

Lotte Moise

Member of the Project Policy Board, Sonoma County Citizen Advocacy Program, Fort Bragg, California.

Nathan Newman

Fresno, California is co-author of *Community Placement of the Mentally Retarded*, Charles C. Thomas, 1973.

Robert Perske

Executive Director of the Greater Omaha Association for Retarded Children, Omaha, Nebraska. **Dennis Popp**

Coordinator of Developmental Disabilities Services, Kansas Division of Mental Health and Retardation, Department of Social and Rehabilitation Services, Topeka, Kansas.

TABLE OF CONTENTS

	<i>Page</i>
Introduction	xi
PART 1. PEOPLE AND COMMUNITIES	
Ch. I. Community Life and Individual Needs	1
by Carolyn Cherington	
Individual and community	
Changing concepts of need	
Beyond reformation: a new response to needs	
in six dimensions	
Changing elements of specific need	
Stumbling blocks	
Systemic advocacy	
Ch. II. Listen! Let Us Speak	1927
by Robert Audette	
Ch. III. Whom Do We Call Retarded?	
by Gunnar Dybwad	37
PART 2. RIGHTS AND INDEPENDENCE	
Ch. IV. The Retarded Citizen and the Law	
by Donald Freedman	
The nature and origin of rights	
Advocacy of rights	
Due process and the rights of retarded persons	
Guardianship: a case example	51
Implications for the future	
Ch. V. The Goal of Independence	
by Jennifer Howse	
A new national goal	
Achieving a goal of independence	
State efforts to achieve the goal of	
independence	
Implications of adopting a goal of	
independence	61
Implications for community agencies	
Ch. VI. A Parent Speaks	
by Lotte Moise	
Right to respect	

Regard for opinion
Room for difference
Risk taking
Responsibility
Readiness for role change

PART 3. HOME AND COMMUNITY

Ch. VII. What Is a Home? 73 by Lotte Moise

Size of Homes
Location
Rooms and furniture
The right to individual lifestyles

Ch. VIII. Creating Community Homes 81 by Nathan Newman

The facilities
Protective laws
Staffing
Staff training
Recognition
Monitoring
Supportive community action

PART 4. SERVICES AND COMMUNITIES

Ch. IX. A System of Services 91 by Sheldon Gelman

Goals of the service
Functional components of a service delivery system . . Human management services . .
developmental and educational services . .
health services . . leisure time and recreation-
ational activities . . vocational and employ-
ment services . . family resource services . .
income . . maintenance programs . .
residential services . . advocacy and
protective services . . regulatory services . .
administrative services . . public awareness
activities

Ch. X. One Service System at Work 105 by Brian Lensink The challenge

The ideology	
Developmental model, specialization, continuity, integration, dispersal	
The structure of the system	
Division of Developmental and Vocational Services	
Division of Residential Services	
Division of Family Resource Services	
Division of Central Administrative Services	
Consumer involvement and monitoring	
Ch. XI. Service Delivery in Rural Areas	129
by Dennis Popp	
Case-finding, information and referral services	
Prevention	
Diagnosis and evaluation	
Home training services	
Infant development centers	
Educational services	
Adult services	
Recreational services	
Counseling	
Ethnic services	
Ch. XII. Outreach in Urban Areas	143
by Thomas Graf	
The special problems of poor families with mentally retarded members	
The example of adult services	
Specific outreach strategies	
Administrative auspices, human resources, program components	
A national call to action	
PART 5. ACTION AND ADVOCACY	
Ch. XIII. New Directions for Volunteers	163
by Robert Perske	
Some new directions	
Public attitude change, agency monitoring, pilot parents, citizen advocates, programs to find guardianship, youth relationships, action in low economic sectors, human and legal rights, program innovation, power of ad hoc task forces	

All volunteers are advocates
Some hard facts that must be faced
Some hopeful opportunities

Ch. XIV. The Politics of Community Action 173
by Thomas Holland

Advocacy for retarded persons
Documentation of needs and potential services
The allocation of services in the community
Inventory of resources for influence
Persuasion
Inducements
Constraints
Matching resources to objectives
Implementing and monitoring the action plan

SUMMARY 185
by Ruth Freedman

INTRODUCTION

Normalization
Developmental model
Dignity of risk
Right to treatment
Right to choose
Ability, not disability
Individualization
Independence
Accessibility
Alternatives
Community alternatives
Community

These terms, the watchwords of our current thinking about mental retardation, connote that retarded people have entitlements to an existence and a style of life which approximate reality as the rest of us experience it. By their existence, the terms also imply that retarded people are usually treated as abnormal, static, dependent, and unfeeling. Because of a strong belief that retarded people are somehow less capable than they really are, and, above all, less human than others, society has built "special" environments for them. Too often, what makes these environments "special" is primarily their abnormal, static, dependent, and unfeeling quality. In the present quest for "normalization" and other ideals, we are working for community alternatives, for one of the most "special" environments for mentally retarded persons has been the institution, away from the community. If these community alternatives are to be any more truly human and "normal" than the institutional alternative and some community alternatives of the past, we must begin by thinking about what living in the community means to us.

In the past, few of us even considered the idea of community whether our community was a large urban neighborhood or a farming village. Most of us have always lived in the community. Therefore, only when something goes wrong with us or with the community itself do we examine our living in it.

Community living challenges the field of mental retardation because so few retarded people have lived successfully in the community.

In recent years, more people have begun thinking about what living in the community means because things do seem to have "gone wrong." During the post-War years of relative peace, riots, racial conflicts, rising crime rates, overpopulation, pollution, and the decadence of physical environments in American communities forced us to examine more carefully our tastes and preferences about community life. Under particular stress in these times has been our ability to get along with people different from ourselves. Our tastes and preferences have surfaced as prejudices. People are moving away from those who are threateningly different. By using exclusionary tactics, many of these people aim to build more homogeneous communities and thereby to fulfill their quest for peace and meaning. Those excluded because of their race and poverty are left to dwell in decaying physical environments. For their part, they are demanding community control and power over their territory, whether in rural areas of the midwest and southwest or in the urban neighborhoods throughout the nation. Finally, interest is growing in communal forms of life, and particularly younger people are attempting to create new communities which conform more closely to their sense of values. People are more actively searching for a way of living in the community at a time when "community" seemed to be a lost ideal.

With community life painted in these hues, it may seem ill-advised to talk about exposing retarded people to the tastes and preferences of others. Should we try to build community alternatives in every community, including those decaying and so full of trouble? Should we challenge the will of people who seem so sensitive to differences from themselves? Should we, in short, expose retarded people to the risks of community life? The authors of this monograph clearly believe we should. Not only should retarded people be entitled to the "dignity of risk," but they should not be considered so different from others. We are not "exposing" a deviant group to the test of reality. We are trying to enable human beings to live as human beings. And that means that some retarded people will live in decaying neighborhoods because that is home. Retarded people will live with us, wherever we are, because we are people, like them.

PART



PEOPLE AND COMMUNITIES

CHAPTER I

COMMUNITY LIFE AND INDIVIDUAL NEEDS

by Carolyn Cherington

INTRODUCTION: INDIVIDUAL AND COMMUNITY

The new terminology in mental retardation—"normalization" and "developmental model," in particular—imply significant changes in our thinking about the nature of retarded people. Since this monograph is directed toward people in communities, we must consider the nature of community living. If we really are to enable "normalization," we must discuss the needs of retarded people in reference to normal lifestyles in communities. To create a special set of needs concepts because retarded people are in some sense special would be to create a conceptual institution of sorts, an island of concepts which, if actively used, would isolate retarded people just as much as have our physical institutions and special programs in the past.

The introductory remarks to the monograph presented the belief that most people yearn and strive for lives which give them peace and a sense of meaning through work or some other productive activity. How is a person, any person, enabled to live peacefully and productively in his community? The answers to such a broad question will undoubtedly vary widely with the individual characteristics of that person, as well as with features of his particular community. What enables one person to live peacefully and productively in his community might not enable another to live well in that community. Similarly, the same factors might not enable a person to live in any other community as well as he does in the one he is accustomed to.

What, then, are some common factors about a person and his community which enable that person to live well? The person, if he is to be self-sufficient, must have the skills basic to survival—to provide for his shelter, food, and physical maintenance. Self-sufficiency in our world also suggests comfortable social interaction, a family, a job, an education and recreation. These are *universal human needs*. If a person is incapable of complete self-sufficiency—as is true of many of us, retarded

or not—someone else must help him either to acquire survival skills or to meet those universal needs. At some time, most of us get help from friends and family in these areas of life; most of us get help, too, from public entities such as educational systems; and many of us get special help in areas that cause us difficulty throughout our lives.

What about the community? Perhaps the "quality of life" of the community allows a person to live well there. "Quality of life indicators" include opportunity for individual status achievement; equality of opportunity for both sexes of all racial and economic groups; living conditions; agricultural and technological development; economic status; education, health, and welfare; and state and local government characteristics.¹ But many people can live well in communities which would be rated low by these indicators. An individual would probably not choose to move away from a community where he felt at home, no matter how poorly the community fared on objective ratings of its quality.

Unfortunately, no studies exist to tell us what makes a community good for one person and not good for another. Clearly, however, a critical factor, a factor implicit in many of the "quality of life indicators," is the extent to which the community enables the individual to develop and to maintain himself there. Underlying this factor are the attitudes of that community toward its individual members. Many sociologists would suggest that if the community is homogeneous and an individual conforms to community expectations, that person will probably be able to live well there. Independent factors cannot be systematically extracted from the nature of communities and the nature of individuals to tell us how to find the best "match."² In addition to the fact that individual preferences vary despite the quality of life, as objectively rated, there is the reality that the community itself reflects its membership. In some sense, then, an interaction between community and individual characteristics will predict harmony or discord.

Let us now say that the person in question is and functions as one who is "retarded." What would enable him to live well in his community? First, he would have to be able to meet his universal human needs. He would need to develop survival skills or obtain resources from outside his own means to meet his needs for shelter, food, physical maintenance, and social

¹ Ben-Chieh Liu, *The Quality of Life in the United States*. Kansas City, Missouri: The Midwest Research Institute, 1973.

² A similar concern makes computerized matching of clients to service programs a questionable practice if used in isolation from other considerations. This is not just a hypothetical concern, for such systems are underway in several states.

living. Because he may need more than ordinary help in some or all of these areas, the community or significant elements within it would have to be disposed to assist him. And to do this the community would have to accept him as a member. The person who is retarded would need to possess or be shown to possess some characteristics in common with community members. Perhaps, like others in the community, his values include working hard and living peacefully. In fact, most communities will accept a retarded person who manages marginally unless he is labelled retarded, at which point many indeed will reject him. Experience with deinstitutionalization efforts indicates that some communities tend to reject retarded people who are labelled as such. The community sees them as strangers from another world. On the other hand, retarded people who are enabled to grow and develop naturally within their communities are seen as legitimate members, and are not so easily rejected. Between outright rejection and overt acceptance, too, are many ways of rejecting retarded people—subtle, seemingly benevolent ways. Many of the special restrictions placed by governments on the locations and types of residences which retarded people may occupy or the creation of special recreation hours at community facilities are examples.

To conclude, two implications stem from our efforts to enable "retarded" people to live well in communities. First, we must continue to inform community leaders about plans for community alternatives and about retarded people themselves.³ Second, we must be sensitive to the sometimes inconsistent-appearing messages which we deliver. While on the one hand the town fathers hear us saying that retarded people are not much different from the rest of us and that we want a normal environment for them, on the other hand, they hear us planning and demanding "special" efforts and appropriations. Progress will require much understanding and patience of all persons. In time, retarded citizens will become their own best advocates and examples.

CHANGING CONCEPTS OF NEED

Until very recently public policy and professional practices treated retarded people as "deviant" members of society; and not long ago we did not consider their "needs" at all. Rather, we considered the needs of society to be protected

³ See remarks by Nathan Newman on this subject in Chapter VIII.

from deviant persons. Wolf Wolfensberger has painted an eloquently disturbing and well-researched picture of our historical abuse of retarded people.⁴ His work clearly shows that retarded people have always been seen as deviant beings, not really as people, much less as people with needs to which we could and should respond.

The earliest progress differentiated between varieties of deviancy. For centuries paupers, insane people, and retarded people had been grouped into poor farms and asylums. In the mid-1800's researchers and social reformers gave us evidence which showed clear differences among the groups. This led to an early attempt to reform retarded people through education (1840—1880), an attempt which was later seen as a failure. Then a period (1880-1925) which Wolfensberger terms The Age of Indictment, a time when retardation was thought to lead to other social ills and public policy was directed toward the eradication of retardation through isolation, segregation into institutions, and sterilization. Finally, during the Depression and War years (1925-1950) retarded people were simply neglected, placed as they still were in large, economical, congregate institutions, segregated from society. During all of this time, through what Wolfensberger calls the Age of Neglect, the needs of retarded people were not the basis for the way we treated them. It was society's need for protection from deviance.

Unquestionable, the parents' movement (ARCs and NARC) led us into what might be called The Age of Reformation which reached a crest in the 1960's. The national leaders of this movement, the National Association for Retarded Children, promulgated early goals in the document *Blueprint for a Crusade*.⁵ The early goals reveal a commitment to dispelling prevailing ideologies about mental retardation and a bold intent to affect the public and professional establishments of the day: emphasis was placed upon research, professional training, and public information. Specific to the issue of needs, NARC aimed to have retarded people recognized, for purposes of *economic needs*, as "permanently and totally disabled"; to have them accepted as "handicapped" for purposes of federal *rehabilitation* programs; and to allow them to receive appropriate

⁴ Wolf Wolfensberger, "The origin and nature of our institutional models," in Kugel, Robert B. and Wolfensberger, Wolf (eds.), *Changing Patterns, in Residential Services for the Mentally Retarded*, Washington, D.C.: The President's Committee on Mental Retardation, 1969, pp. 59-171b.

⁵ National Association for Retarded Children, *Blueprint for a Crusade*, New York: National Association for Retarded Children, 1954.

*diagnosis and evaluation.*⁶ State and local ARCs were assisted in actions to improve *special education, residential care, and community support services.*

In 1962 the federal government first gave concerted attention to these issues as The President's Panel on Mental Retardation delivered its report *National Action to Combat Mental Retardation.*⁷ The document reflects some of the best professional opinion of the time about needs of retarded people. The very existence of the report and its far-ranging thought indicate the public and professional progress made since The Age of Neglect. New organizational and administrative concepts were suggested for both federal and state coordination of programs for retarded citizens. This report put forth two new service delivery concepts which underlie present-day approaches to meeting the needs of retarded people. It urged a *continuum of care* throughout the retarded person's life-time and a *fixed point of referral* which would keep in touch with the family and/or the retarded person to ascertain what service needs were met. Substantively, emphasis was placed upon *detection, evaluation and medical care, recreation, religious education, education, vocational rehabilitation, training, employment, and residential care.* Significantly, the report viewed residential care primarily as that offered by state institutions, although it recognized other alternatives as desirable. Then, as now, it was expected that generic services would meet many needs. It differed from today's view, however, in that we have come to see the responsibilities of generic agencies in light of the *entitlement* of retarded people to generic services. The 1962 report, on the other hand, relied heavily on enhancing specialized attention by generic agencies through financial incentives, specific law reform, and coordinative mechanisms at the national, state, and local levels. Planning grants to the states were recommended to foster "comprehensive planning in mental retardation" since it was asserted that primary leadership in direct services was a state responsibility. And subsequently, Congress did appropriate funds for state planning, implementation, and initiation of community facilities.

The attention given to retardation by the national and state governments and by voluntary associations between 1950 and 1970 resulted in states developing broad plans in retardation. These plans improved, amplified, or altered the national plan

⁶ Success in achieving these labels for retarded people did help to gain recognition and funds from federal agencies but served also to complicate messages about normalization, as noted on prior pages.

⁷ President's Panel on Mental Retardation, *A Proposed Program for National Action to Combat Mental Retardation*, Washington, D.C.: U.S. Government Printing Office, 1962.

according to lively interest and progress developing within the individual states. Almost every state created improved and more visible coordinating mechanisms for retardation at both the state and substate levels; special services increased throughout the "continuum of care"; and many state and federal laws were written or revised to include special services for retardation. Many areas needed further work, however. These areas included the unresolved role of our large institutions and the development of comprehensive non-institutional residential services, specific strategies and policies for prevention, the entitlement of retarded people to education and to humane and unrestrictive treatment, the dilemmas of retarded people living in poverty, and refinements in planning for the needs of retarded individuals at all levels of capability and age. At the federal level, the President's Committee on Mental Retardation has examined most of these areas; in the voluntary sector Associations for Retarded Citizens and others have gone to court and won entitlements; at the state and community level significant efforts are being made to develop high quality, community-oriented services including residential alternatives. Because the way has been so long, though, many of the reformation efforts have been either bandaid or bootstrap operations—redressing the wrongs in existing programs, starting new kinds of services from scratch, creating basic structures at the state and local level to plan and deliver services, increasing the quantity of services, and beginning to insure their quality. *MR 68* documented strides in *early education, day care, vocational training, employment, and residential care*. But in many communities of the United States, the vision of the 1962 President's Panel report for a continuum of care and a fixed point of referral for all retarded people remains unrealized.

BEYOND REFORMATION: A NEW RESPONSE TO NEEDS IN SIX DIMENSIONS

What, then, are thought to be the needs of retarded people living in the community today? As suggested at the outset, we should first consider universal human needs. If retarded people are to live as the rest of us, their needs should be considered as needs of the rest of us, according to the *dimension of universal human need*.

The President's Panel in 1962 (and many state plans) considered grouping needs according to physical and mental

health, shelter-nurture protection, intellectual development, social development, recreation, work, and economic security.⁸ The Panel report suggested that these needs would vary primarily with the individual's age indicating a continuum from infancy through adulthood. This presents a second dimension of need, *the dimension of age*.

Since the President's Panel report, our thinking has progressed about the varying needs of individuals limited in capability. Applied to institutional and community programs for all retarded people, the philosophy of normalization challenges us to perceive better ways of meeting the needs of retarded people of all degrees of capability. We must add to our conceptions a third dimension of need, *the dimension of capability*.

The "developmental model," promoted as responding best to our goals of normalization and community life, incorporates three basic assumptions: (1) Life is a process of change, and retarded people change as do the rest of us; (2) Development takes place in a sequential, orderly, and predictable manner; and (3) The rate of development can be influenced.⁹ To conform to the developmental model and its assumptions, any consideration of needs must recognize that universal human needs change not only according to age, but also according to capability and development. Thus, *the dimension of change* should remind us that the needs of an individual will alter with his aging and his changing capability as he develops.

Our historical treatment of retarded people has instructed us in the hazards of treating groups of persons as masses of deviants rather than as individual people. One can see the results of mass treatment in the dehumanization which has occurred within our large congregate institutions. Perhaps even more striking and sobering is the evidence of recent research in social psychology which suggests that a normally gentle person will engage in violent acts as long as the situation allows him to depersonalize both the victim and himself.¹⁰ The past should certainly instruct us in the need for *the dimension of individuality*.

When we think of people as masses we forget that each individual is different. Individuals grow, develop, and age differently. Retarded people, like all people, have different

⁸ *Op. cit.*, p. 76.

⁹ National Association for Retarded Children, *Residential Programming for Mentally Retarded Persons, A Developmental Model for Residential Services*, Arlington, Tex.: National Association for Retarded Children, 1972.

¹⁰ Stanley Milgram, *Obedience to Authority, An Experimental View*, New York : Harper and Row, 1974.

abilities and disabilities. And each individual has a unique personality. We can forget, too, that retarded people are citizens with rights. When thinking of people in categories, we often design airtight "systems" of services, which quickly lose their actual sense of purpose and come to exist and self-perpetuate for their own purposes. It is no wonder that many individuals in need are lost or forgotten by the service system.

Obviously we must consider the needs of groups and create systems. But in designing such systems, we should build in reminders to ourselves of the individuality of the client. We can make services personal, responsive, and accountable. We can start with very basic (universal) elements of human need; and starting from the smallest units of personal need, rather than from agency needs or system needs, we can weave a system which will not by uncontrolled growth evade its basic reason for being—the individual person who needs it. Thus, another dimension for considering the needs of retarded people in the community should be the dimension of individuality, a series of reminders, catalysts, and safeguards which help insure that no one gets placed, lost, or trapped in an inappropriate spot in the system.¹¹

The sixth dimension stems from the dimension of individuality for it is a special aspect of that dimension. If a system truly respects an individual, it recognizes individual preferences and tastes as the key to the decisions made within it. *The dimension of choice* should allow a person served by a system of services to be the ultimate decision-maker about the tailoring of services. People choose occupations and vocations, places and ways to live, and friends and companions. Choices make a person unique and underpin his dignity and freedom. Choice, in short, is the fullest exercise of individuality and independence. Without choice, a person is but an object of the choices of others. Even if a system were carefully tailored to meet individual needs, it could neither allow the developmental model to operate to its logical conclusion nor enable the realization of normalization without the dimension of choice. Unless a person has the power and responsibility of choice he is to all others an object. Most especially, he is less human than others. A system of human services above all should respect the choices of those who use it, whether those people are called retarded or not.

¹¹The cynical reader will at this point recognize **that** even such safeguards cannot insure the development of a *working* system which remembers the individual. The imperatives of political, organizational (bureaucratic), and economic life are such that there needs to be a way of checking *ourselves* as planners, service givers and supporters, a way of insuring that we continue to discover our errors of omission and commission. Comments on this problem are to be found in the final remarks.

CHANGING ELEMENTS OF SPECIFIC NEED

All persons have the same universal human needs: shelter, health and physical development, and personal and social growth. The dimension of capability will, of course, very clearly define gaps in the dimension of human need.

Shelter. A person living normally will own or rent his own home, although many of us will need financial assistance. One whose capability is somewhat lessened may choose to live in a supervised apartment dwelling, a group home, or a foster home. One even less capable at a given time may live in a nursing home or a general hospital. During his lifetime, he may choose to move from one type of dwelling to another, because of his age or his changing needs. A child whose own family cannot care for him may live with a foster family; he may need to be with a foster family only temporarily, on weekends, during vacations, or during a personal or family crisis.

Health and Physical Development. Most of us can arrange for our own medical care and get what therapies we need on our own; so can many retarded people. Almost all of us need some help in learning to use health services or paying for them. A person whose health problems are more serious will need specialized services and therapies. Some will require constant supervision and intensive therapies. Again, these needs may change with age and growth. They may become more intense, as they do for all of us in old age, or they may become less so if therapies are effective. Similarly, the most capable of us are able to buy and cook our own food. All of us will have to be taught how to do these things, however. If we are retarded, learning may take us more time; perhaps we will need financial assistance to buy our food and maintain our health. Those retarded people with the most limited capability will need to have their food prepared for them and help to eat it. Much progress has been made in teaching the most handicapped to feed themselves; so that we can expect almost everyone's need for help with nutrition to lessen with age and development. Physical disabilities mean that some of us need help getting around our homes and communities. All of us need help when we are very young. A few retarded persons may never be ambulatory, but physical development can be facilitated greatly for most.

Personal and Social Growth. Everyone needs some education to survive in the interpersonal and vocational world. Most retarded people can be educated to meet their needs through

public school systems. Some will require a very intensive program of individualized education; and for a few, education will consist primarily of very basic training in life skills. Education should begin very early for those whose capabilities are limited. Most retarded people can be trained for employment or for chosen work activities which are personally rewarding. Many will eventually hold down their own jobs in industry; some will need help finding and fitting into regular employment; some could work better in a sheltered work station within industry; some should be employed in an even more sheltered situation; a few will gain satisfaction from work activity programs and planned recreation. Most will be able, with some initial guidance, to plan and carry out leisure activities with their peers. A good many will need counsel in making decisions about legal issues, money, marriage, and sex; and some will need mental health services.

Only great vigilance will assure that a retarded person's changing needs are met in ways appropriate to his capability and to his age. Moreover, as simple as the foregoing discussion seems, only a complicated planning effort could enact the elements of a service system which will respond to changes in individual needs. A given individual could be charted on the basis of his needs at any given time in his life and stage of development. The individual might have a serious incapacity for health maintenance, but he might be capable in terms of personal and social skills. Thus, a given individual might appear incapable in some respects and very competent in others. Our past mistakes included a tendency to group people in multi-purpose institutions or programs according to only one criterion of need; hence, we find severely physically disabled people with significant vocational potential inappropriately grouped with mobile individuals capable only of sheltered activity into an institution serving "profoundly retarded." Similarly, it is not unusual to find aged persons of limited mobility but with potential for activities appropriate to their age placed on back wards of large institutions, being treated as children and even "trained" for youthful activities. Very frequently, adolescent individuals are likewise kept childlike in their personal and social lives. *The dimension of change* demands that we realize that aging and development alter an individual's profile of needs.

Every system of services should be analyzed according to how carefully it facilitates an individual's movement to elements of services appropriate to his changing needs. To what extent a system can fulfill our criteria will depend in part upon the extent to which its elements are financially and geo-

graphically accessible to those in need. But it will also depend upon the adequacy of the processes which comprise *the dimension of individuality*. Such functions as appropriate diagnosis and evaluation, information and referral, case management and periodic treatment planning, personal advocacy, protective services and follow-along offer the individual some safeguards against anonymity and abandonment. The *dimension of choice*, aided by these functions, will keep things moving in an appropriate sequence at the appropriate time.

An example of how one area of need (shelter) can be properly considered by the "system" within the five other dimensions is provided in the following hypothetical case and the accompanying chart.

JOHN'S MANY HOMES: HYPOTHETICAL CASE OF AN INDIVIDUAL'S NEED FOR SHELTER

As an infant this retarded individual lived at home and being non-ambulatory had a limited degree of capability. As a child, and through adolescence, John remained with his family. When he reached adulthood he lived first in a group home and later in a supervised apartment. Because of his poor health in middle age, he stayed a few months in a nursing home but later moved back to the apartment.

At point A John seemed to his parents to be very "slow" developing, and the doctor advised the family that their son was "moderately retarded" and should be placed in a state institution. A careful evaluation by the institution's admissions department revealed that the family, with help, could provide good care and training; and supportive services were mobilized to help them and to follow him along through his progress in a special class and vocational training. Although he tried out several kinds of work, he liked the physical work and sense of satisfaction which he got from cleaning and janitorial work. At 22, with help from his school's vocational department, John got a job as a janitor and enjoyed this work for many years.

At point B the family once again considered sending John to an institution because of the parents' advancing age and their fears about his survival alone. Here, a plan for guardianship, a personal advocate, and protective services were arranged; John moved to a group home, retaining his job and forming close friendships at his new home.

At point C he moved into a supervised apartment with

three other men from his group home. John's personal advocate wondered if any of the men would like to join a bowling team. Two of them did not want to join in competitive sports but preferred to spend time on hobbies. John had always liked sports and joined the team, which won its league several times.

At point D John entered a general hospital for a brief period, suffering from a serious bout with virus pneumonia. When he was somewhat recovered, the hospital mistakenly recommended that he go to the state institution infirmary to recover fully. His advocate met with the institution staff, and together they were successful in locating a good nursing home near the apartment where his friends were still living. He stayed in the nursing home for two months and was happy to return to his own apartment.

John lived a life not much different from the rest of us. In part, he was lucky to live in a community where resources were available to help him do so. The example shows, however, that vigilance must be built in to keep the resources responsive.

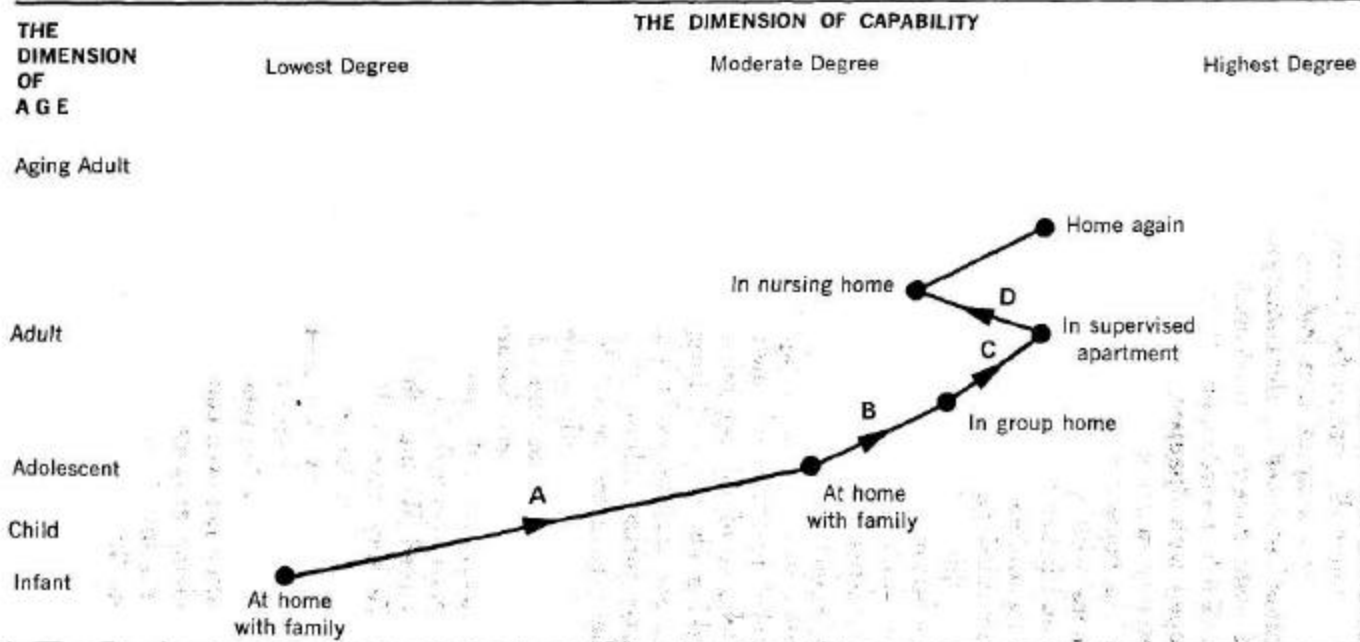
STUMBLING BLOCKS

An ideal is an ideal. Recognizing this, let us now turn to some of the constraining realities: the real imperatives of political, organizational, and economic life. Remembering the past, we should acknowledge that harsh pressures will push us to compromise our ideals to protect society from the confrontations it does not want to make. No society is eager to confront its mistakes and its often less-than-human priorities or to confront people who remind us of our own less-than-beautiful, less-than-brilliant parts. Will we know when we are compromising? To be certain that we know will be difficult, but the first step is to reject our compromise "consumer participation" and to build into policy processes at all levels a voice for consumers themselves and an ear to listen well.

The complexity of organizational and bureaucratic life will make our task increasingly difficult. Complexity reigns in the sources of funds upon which we rely, not only in the variety of sources, but also in the machinery attached to them. Complexity governs the labels we must use, the inter-governmental relations, and the limitations placed upon the uses of funds. Regarding the labeling issue alone, consider that for federal funding we will have to prove that retarded people are variously disadvantaged, crippled, developmentally dis-

JOHN'S MANY HOMES

Hypothetical Case of an Individual's Need for Shelter



Note: Movement of the line indicates the dimension of change which occurs in a person's need for shelter as he develops and ages.

The dimensions of individuality and of choice are highlighted by critical decision points (A, B, C, D), discussed in the case example.

abled, substantially handicapped, former or potential welfare clients, or persons with special needs. One can easily see how we get locked into damaging attitudes. It is easy to see how we confuse consumers. We are probably confused ourselves.

As another reality of bureaucratic life, "human services reorganization" is sweeping the country with massive reorganizations of state government accomplished in nearly half of the states. While retarded people suffered from being physically grouped with "paupers and insane" in the 1800s, they have suffered from being bureaucratically grouped under "mental health" in more recent years.¹² Now they are grouped in bureaucracies with even broader concerns. The rationale of efficiency and better human service delivery, while admirable in its own right, does not apply well to the particular individual needs of retarded people. We will have to be alert to design "systems" within the human services structure that have an *identifiable* subsystem, such as the one described earlier in these pages, which responds to the human needs of retarded persons in particular.

Perhaps one of our greatest stumbling blocks is economic. The necessity to economize tempts us constantly to lose sight of needs; yet resources—human, financial, and capital—are limited. Because of this we must economize, and economizing means making choices and foregoing opportunities, drawing boundaries and making exclusions. The nature of major financial resources further inhibits choices and constricts boundaries. Most of these resources are not designed especially for retarded people. At best they would serve retarded people along with other "categories" as mentioned above. Thus, as we choose a particular funding source, we are often constrained to exclude some individuals from the service segments which that source favors. We must also make choices which limit the geographical areas to be served. We must find particular locations for service facilities. We may have to focus our services on a particular segment of the population. Every choice implies foregoing other choices. Thus, any choice—be it geographical, locational, or population-based—means that some people will lack a particular service. And some retarded persons' pressing needs will not be met, often not even considered.

Economizing also means trying to achieve the most "output" for one's investments. "Cost effectiveness," "economies of scale," and "marginal utilities"—terms and methods which have begun to flood the human services field as it strives to

¹² Gunnar Dybwad, "Psychiatry's Role in Mental Retardation", in Bernstein: *Diminished People*, Boston: Little, Brown and Company, Inc. 1970, p. 144ff.

appeal to the purse—simply ask, "Can we afford to invest in this business?" The massiveness of institutions for retarded people was at least in part due to "economies of scale." The preference of rehabilitation and other programs for concentrating on the person with high potential for "output" reveal a "cost effectiveness" mentality. And clearly, in political terms at least, the "marginal utility" of investing in retarded children and encouraging investment in them was for a long time considered greater than investment in retarded adults.

Philosophically, we have begun to overcome these narrowings of concern. We will be continuously tempted, however, indeed we will be constrained, to document our "cost effectiveness." And this will try the mettle of our new philosophies. If we do not persist, our systems will not meet many retarded people's needs or, again, even consider them. Especially excluded will be those who are less capable.¹³

Few would disagree that we should account for the investments made in our clients. Certainly, people are entitled to know what happens to their money. On the other hand, a strictly economic justification can probably never be achieved in the human welfare field. It is neither possible nor desirable to quantify all human needs and all of the benefits of programs designed to meet them. The trend toward "individual treatment planning" for consumers of human services is healthy, for it recognizes this reality and places the accountability issue more appropriately between the consumer and the agent of service. If indeed such individual treatment plans can generally demonstrate their worth for the consumer, the challenge to us will be to convince the funding agents that this in itself is the fullest accounting necessary.

Few would disagree either that we will always have to make "economizing" choices in applying our resources. Hence, boundaries on staff, facilities, target areas, clientele, and organizational identities will remain.

SYSTEMIC ADVOCACY

Overcoming these problems will require a series of strategies which might be called "systemic advocacy," for these strategies are directed toward advocating the needs of the individual at the level of political, bureaucratic, and economic

¹³ See Ronald W. Conley, *The Economics of Mental Retardation*. Baltimore, Maryland: John Hopkins University Press, 1973.

systems. Systemic advocacy will address gaps in the "service system," weeding out the murky undergrowth of complexity and thinning the massive overgrowth of bureaucracy.

As Robert Perske points out in his chapter, "New Directions for Volunteers," the voluntary movement of parents and friends of retarded citizens can uniquely monitor a system of services. Associations and the ad hoc groups which he describes can watch the elements of the service system, checking within system elements on quality and quantity of services. They can also patrol the boundaries of those elements and locate needs between them. Then they can organize to find ways of meeting those needs. But this unique ability of theirs will itself be constrained by their tendency to perform the service-providing role.¹⁴ As their own service delivering increases, they too must economize and narrow their vision; they will set allegiances to boundaries in relation to the service element and lose perspective on the voids between the boundaries, becoming beholden to funding agents and others whom they should be monitoring and whose boundaries they ought to patrol. The malfunction of such an arrangement is analogous to the clearly documented political theory and research which states that a "crisis in public authority" results when the organized regulated entities become entwined with the regulatory authority.¹⁵

Another kind of systemic advocacy exists within the public sector itself. Although still youthful and some claim problematic in its conception and development, the Developmental Disabilities Services and Facilities Construction Act of 1970 was a landmark piece of federal legislation in its intent: that a state level planning and advisory group review and evaluate the quality and scope of existing services for developmentally disabled people and see that "gaps" are filled. The Commonwealth of Massachusetts has given the program the leadership of a staff (Bureau of Developmental Disabilities, Executive Office of Administration and Finance) and a planning and advisory council (Mass. Developmental Disabilities Council) which has had extensive experience in planning and advocating for retarded persons. Here, an exemplary approach to fulfilling and even going beyond the federal legislative intent has resulted in a public social planning method which directly addresses the problems of boundaries and the gaps between them. A major emphasis is placed upon the reform of discriminatory public

¹⁴ Wolf Wolfensberger, *The Third Stage in the Evolution of Voluntary Associations for the Mentally Retarded*, Toronto: National Institute on Mental Retardation, 1973.

¹⁵ Theodore Lowi, *The End of Liberalism*, New York: W.W. Norton & Company, Inc., 1969, pp. 86-90.

policies and not upon the design of "special" (segregated) efforts.¹⁶ Working closely with other public and private agencies, the Council and its staff seek to fill gaps by reforming both federal and state legislative and administrative law, by "seed-ing" and supplementing gap-filling efforts of other organizations, and by stimulating the policy analysis and reform efforts of others. As noted in the case of the voluntary movement role in monitoring and patrolling boundaries, a key to the objectivity and comprehensiveness of this form of "systemic advocacy" is the relative freedom of both the Council and its administering agency from the direct service delivery functions.

The final, perhaps ultimate, systemic advocacy method uses judicial recourse on behalf of the rights movement. The movement toward the guarantee of rights to education and treatment and the right to the least restrictive alternative, of course, results from the two previously cited forms of advocacy. But judicial recourse and its results deserve mention as a separate form. The rulings which have already been made have provided great force to "deinstitutionalization" efforts and have served as important tools in the change process through executive and legislative branch channels. The rulings and the ensuing legislative and executive policies directly relate to this chapter. They are intended to cut through the political, bureaucratic, and economic constraints to guarantee *individual* rights. And some would argue that only such fundamental reforms can guarantee that an organized society will respond to the human needs of its members rather than its represented interests.

¹⁶ Some documentation of the approach can be found in Bureau publication, *A Guide to Service and Exclusion Policies in Public Programs of the Commonwealth for Retarded and Multi Disabled Persons*, 1970, and in the Council's State Plan for 1973.

¹⁷ Theodore Lowi, *The Politics of Disorder*, New York: Basic Books, Inc., 1971, p. 177ff.